

The Texas Traumatic Brain Injury Advisory Council Presents a



Statewide Action Plan of Supports and Services

for Persons with Traumatic Brain Injury and Their Families

March, 1999

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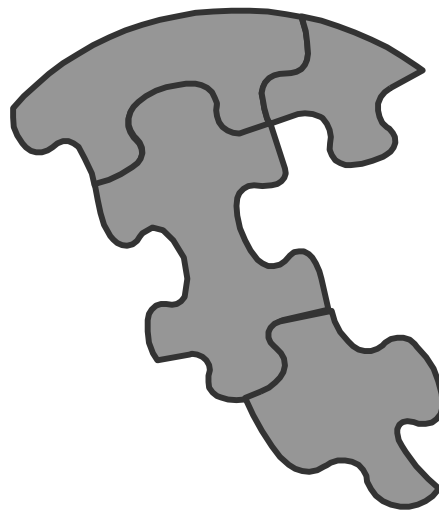
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Statewide Action Plan of Supports and Services

for Persons with Traumatic Brain Injury and Their Families

*Presented by The Texas Traumatic Brain Injury Advisory Council
March, 1999*



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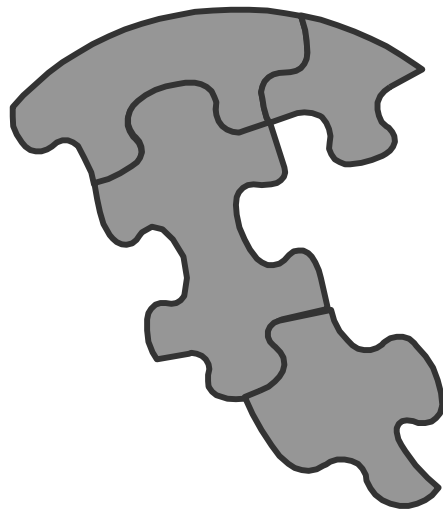
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***The Public Health Crisis of
Traumatic Brain Injury is a Public
Policy and Funding Issue***



THE PUBLIC HEALTH CRISIS OF TRAUMATIC BRAIN INJURY IS A PUBLIC POLICY AND FUNDING ISSUE

Lives must be saved:

Over the last twenty years incredible life saving measures and technologies have been developed and employed to save the lives of people who would have otherwise died as a result of a traumatically induced brain injury. These extraordinary measures are wonderful, but, as a result, Texas is faced with a growing population of individuals and families living with the effects of traumatic brain injury.

As long as Texans continue to sustain traumatic brain injuries, public policy needs to be addressed. Texas is doing a remarkable job of saving peoples' lives, but doing a very poor job of providing the necessary supports and services for these individuals and their families after the trauma occurs.

The life changing losses and effects, which most individuals with a traumatic brain injury experience escalate when the needed supports and services are unavailable or inaccessible. When this happens, Texas pays in ways more costly than it would have had the requested supports and services been available at the time of need. **Some or all of the following changes, losses or issues “may” happen to anyone who sustains a traumatic brain injury and to their families.**

How does the State of Texas pay?

- ◆ Contributing members of society become consumers of publicly funded systems as they lose their jobs, can't return to their pre-injury employment and face great difficulty in securing and maintaining new employment.
- ◆ Family members frequently leave their jobs because they must become the primary care giver. Their disposable income plummets, their tax contributions are reduced and some are required to turn to public support.
- ◆ People who are in the high-risk age group of 15-25 for brain injury do not have adequate private insurance to cover medical and long term care thereby resulting in an escalation of uncompensated or publicly funded care.
- ◆ People with traumatic brain injury are inappropriately placed in nursing homes or other institutional settings.

- ◆ Many students, with traumatic brain injury are not able to achieve at their pre-injury grade level, face failure and drop out, thus leaving them devoid of the basic preparation for their future adult needs.
- ◆ Divorce among persons with traumatic brain injury and their spouses, is the highest of all disability groups.
- ◆ Families disintegrate resulting in estrangement and isolation.
- ◆ Families expend all their savings, get into debt or go bankrupt in an attempt to pay for supports and services for their family member with a traumatic brain injury.
- ◆ Adults unable to live alone frequently return home to live with aging parents.
- ◆ Individuals without support systems have a high probability of becoming homeless, jailed, institutionalized in state hospitals or dying.
- ◆ Individuals with brain injury who have substance abuse or chemical dependency issues, either pre or post-injury, often have a much bigger problem after the brain injury. This is true for their families as well.

What is the impact to Texas?

1. Employees who can no longer work.
2. People who had spendable incomes now have very little or none.
3. Students of all ages who are not able to complete their educations.
4. Individuals with traumatic brain injury and their families who quickly exhaust their insurance coverage and other resources forcing them to turn to publicly funded programs.
5. An uncoordinated system of health and human services in Texas that is repeatedly unavailable for persons with brain injury and their families at the time of their need.
6. Long term “warehousing” of people with traumatic brain injury in institutional or other inappropriate settings costs Texas far more than effective timely rehabilitation and accessible community-based supports and services.
7. An uneducated public continues risk-taking behaviors resulting in more traumatic

brain injuries and deaths.

Mission Statement

Statement of Need

Purpose



MISSION STATEMENT

To ensure all Texans who sustain a traumatic brain injury access to the supports and services needed for them to return to full participation in all aspects of community life.

STATEMENT OF NEED

Traumatic Brain Injury is a growing public health issue in the state of Texas¹ at a time when the current health and human service delivery system does not adequately meet either the short term or the long term needs of individuals with traumatic brain injury and their families.

PURPOSE

The Texas Traumatic Brain Injury Advisory Council has developed this Statewide Action Plan of Services and Supports for Texans with Traumatic Brain Injury. The Council believes the recommended outcomes, rationale and strategies will result in an accessible and coordinated array of services and supports for individuals with traumatic brain injuries and their families.

It is important to understand two key issues:

1. The services and supports needed by individuals and their families reflected in the Statewide Action Plan generally begin in an acute medical care setting and often continue into long-term community-based supports and services.
2. Not all persons with traumatic brain injury nor their families require extensive supports and services but many do require a few interventions without which the medical, physical, psychological and economic conditions can mushroom into larger needs and more costly interventions.

¹ One (1) Texan sustains a traumatic brain injury every 4 minutes, 18 Texans will be permanently disabled every day by a brain injury, 2 Texans every hour will be hospitalized and 1 Texan will die every 2 hours according to the Centers for Disease Control and Prevention. These figures do **not** include individuals who seek treatment other than at a hospital.

***Texans with Traumatic Brain Injury
Require Supports and Services Distinctive
From the State's Existing System***



TEXANS WITH TRAUMATIC BRAIN INJURY REQUIRE SUPPORTS AND SERVICES DISTINCTIVE FROM THE STATE'S EXISTING SYSTEM

What do persons with traumatic brain injury need?

Texans who sustain a traumatic brain injury and their families have many of the same needs as everyone else. They need a place to live, food on the table, clothes on their backs, relationships and meaning to life. When a traumatic brain injury occurs, the ability to meet any or all of these needs may be endangered as the individual's ability to maintain pre-injury level employment, living conditions, relationships and quality of life plunge.

Due to the disabilities resulting from the traumatic brain injury, people need help achieving their basic needs. The availability of services such as health care and rehabilitation, home and community-based support services, job training and placement, income support and education can make the difference between a wasted life and a fulfilled life in the community.

A prescribed set of services doesn't work -

People with brain injuries do not require a prescribed set of services, but rather the availability of a range of services that can meet individual needs, are diverse and change over time. The order in which services are used can vary. Ideally, services and supports should be flexible allowing people with brain injuries and their families to access services when they need them and not just when the system offers them.

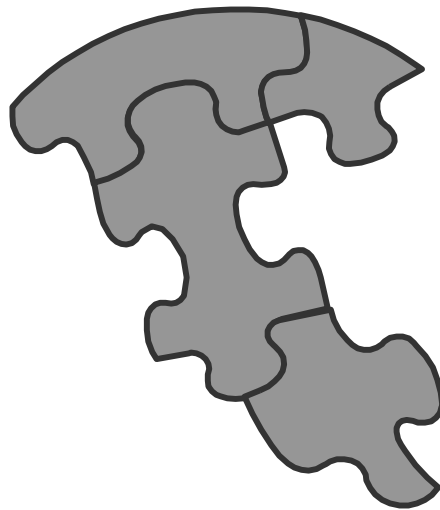
Persons with a brain injury should have control over the services received. To be cost-efficient, the system should allow for individuals to progress to a less restrictive environment, until they reach their maximum level of independence. If options exist in the community, these individuals can avoid stays in more expensive institutions.

The Texas Traumatic Brain Injury Advisory Council recommends to the State of Texas, the following Statewide Action plan of supports and services for persons with traumatic brain injury and their families. The Texas Traumatic Brain Injury Advisory

Council has developed these recommendations as a result of identifying *Gaps in Services*², completing a *Policy Analysis of the Texas Health and Human Service Delivery System*, and surveying a segment of the public through needs assessment surveys and public meetings.

² *Gaps in Services in Texas' Health and Human Services* and *A Policy Analysis of the Texas' Health and Human Services*, and the *Needs Assessment Report* are available as separate documents from the Texas Traumatic Brain Injury Council. To receive copies, please email brain.injury@tdh.state.

Recommendations



RECOMMENDATIONS

Outcome I **Thorough identification of the needs of Texans with traumatic brain injury and their families throughout the state with an emphasis on reaching children and adults who are not receiving services.**

Rationale - **To provide Texas with the data to make informed and responsive policy and funding decisions necessary to provide Texans with traumatic brain injury appropriate and sufficient services.**

Strategies -

1. Conduct a comprehensive needs identification of Texans living with traumatic brain injury and their families.
2. Study the costs and effectiveness of providing Medicaid rehabilitation to eligible Texans with brain injury.
3. Determine the costs of care, the economic impact and the social costs of traumatic brain injury to the State of Texas.

Outcome II **Ensure access and delivery of coordinated and appropriate supports and services for Texans with traumatic brain injury and their families.**

Rationale - **To provide to persons with traumatic brain injury and their families the services necessary to maximize participation in all aspects of community life.**

Strategies -

1. Simplify and publicize the points of entry for the state's health and human service systems.

2. Simplify and consolidate the application process for all state health and human services and make the process available statewide and across agency lines.
3. Facilitate broader access to existing systems by expanding the eligibility criteria of the state's health and human service systems to include persons with traumatic brain injury and their families.
4. Implement cost-sharing measures at all levels of care, in all service delivery systems and across agency lines through the coordination and delivery of services.
5. Ensure that all Texans who require acute medical care for a traumatic brain injury receive the necessary care regardless of the ability to pay.
6. Fund community-based "Care or Service Coordination" pilot projects in rural, urban and border communities as a means to identify community supports and resources, to assist with service access and coordination and to advocate for persons with traumatic brain injury and their families.

Outcome III **Foster the provision of effective and timely information, education and training to providers of services at all levels of care, to persons with traumatic brain injury, to their families and to the public.**

Rationale - **To assure a raised level of understanding of traumatic brain injury by the providers of supports and services to persons with brain injury at all levels of care and to increase the timely access to information, education and resource identification for persons with brain injury, their families and the public.**

Strategies -

1. Conduct a comprehensive needs identification to determine the educational and training needs of service providers to persons with traumatic brain injury and their families at all levels of care.

2. Fund education and training to providers of services at all levels of care.
3. Ensure the establishment of a network designed to provide timely information and referral to persons with brain injury and their families.

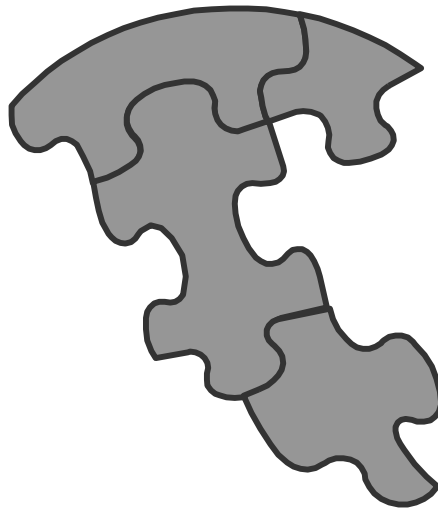
Outcome IV A reduction of preventable traumatic brain injuries in Texas.

Rationale - To reduce the impact of traumatic brain injuries on the lives of Texans because many injuries are preventable.

Strategies -

1. Promote coordination of local and regional injury prevention programs with state, public and private injury prevention programs.
2. Foster programs established on scientifically based policy strategies designed to lead to a reduction of traumatic brain injuries.
3. Promote prevention efforts to the general public.
4. Establish a public awareness campaign about the compelling and potentially disabling or deadly effects of traumatic brain injury.

Summary



SUMMARY

In Texas, we do everything possible to save a life . . . But it is not enough to “save a life,” it is only a beginning. In Texas, we need to answer the hard questions from our decisions to save lives. The necessary services and supports must be available to allow persons with traumatic brain injury and their families full participation in their communities with the ability to exercise control over their own lives.

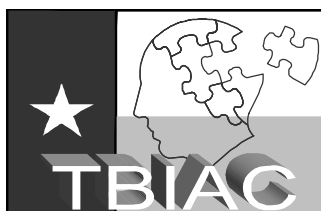
While you read this report, 6 Texans sustained a traumatic brain injury, one of whom was hospitalized. Sometime in the next two hours, one Texan, somewhere, will die from a Traumatic Brain Injury.

It is time to act!

The information presented in these recommendations to the State of Texas is driven by the startling impact that Traumatic Brain Injury:

- ❧ Frequently kills or threatens the life and well-being of the individual who sustains the brain injury.
- ❧ Respects No One - All Texans are at risk for sustaining a traumatic brain injury*.
- ❧ Is the number one cause of death and disability of children and young adults.
- ❧ Frequently occurs as a result of risk taking or reckless behaviors.
- ❧ Is often unrecognized or misunderstood.
- ❧ Is frequently undiagnosed or misdiagnosed thereby leaving the individuals without services and supports.
- ❧ Results in many individuals who look “ok” but are unable to function “ok” and may have lifelong cognitive and behavioral impairments.
- ❧ Is frequently trivialized and misrepresented by the media.
- ❧ Requires appropriate services and supports ranging from acute medical care to long term community-based services and supports many of which are not readily available in Texas.
- ❧ Results in a growing number of Texans with traumatic brain injury whose only service delivery system is a homeless shelter, a prison or a state institution, thereby costing Texas more for their care than it would have had these individuals received the necessary rehabilitation and community based-services.
- ❧ Is an injury whose effects rapidly travels beyond the individual and may significantly affect or alter the family and the community as well.
- ❧ Has a high price tag in terms of lost tax revenues, productivity and the provision of medical care.
- ❧ **Is preventable.**

* Anyone engaged in movement, either as an occupant or rider of a moving vehicle be it motorized or human driven; a participant in activities which involve motion by foot, by machine or by propulsion; someone either engaging in risk taking behaviors involving speed, motion or physical contact or the recipient of someone else's inattention, negligence, or violence.



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